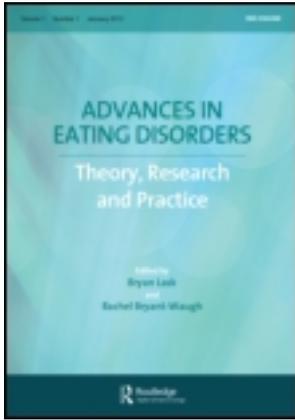


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## PERSONAL VIEW

### The term ‘brain disorder’: a compass or a map?

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The term ‘brain disorder’ seems to cause a range of reactions, some quite strong. I have seen it be transformative, and at other times deeply offensive. Many people even remember the first time they heard the concept applied to eating disorders and their surprise. It often seems to challenge fundamental beliefs. For a few, the idea changed the course of treatment in a positive way. For others, opposing the idea seems to have become a cause in its own right.

Despite the objections, I believe that the term brain disorder may be an opportunity, not a problem. By using it, or at least tolerating it – or other similar terms – we may be better able to mobilize families to achieve what is our mutual goal of full and sustained recovery, free of an eating disorder – a brain disorder.

I use the term ‘brain disorder’ as a compass, not a map. It is a direction, not a prescription. I do so in the belief that that the term offers a new orientation for parents. I would argue that what parents hear and believe is crucial to most patients’ success in recovering and staying well – especially at the most important time – that of diagnosis. Parents are the ones seeking treatment, evaluating treatment options, cooperating with treatment, obstructing treatment – not to mention paying for and driving to treatment. Without the right orientation – which starts with the terms we use to describe the disorder itself – parents may struggle to support their daughter (or son) and the clinical team.

In 2002, I thought I knew everything I needed to know about eating disorders. This was very little and involved a condescending pity and disdain for the sufferer and her parents. My understanding was that an eating disorder was a cry for help from a person damaged by life. After I realized my own daughter had anorexia nervosa my first several encounters with books and local psychologists and a Google search confirmed my early impressions. I started to withdraw into self-recrimination and terror. I had not protected my daughter from harm. I began to abdicate my parental responsibilities to professionals who encouraged that thinking. I started to believe my daughter who had pointed straight at her father and I, and very credibly declared us and the world around her as toxic and her waning health to be a rational and understandable choice.

I was fortunate. I had a clue from my own childhood which nagged at me. My father had been a psychology graduate student and I grew up hearing the history of schizophrenia and autism – where in the absence of another explanation everyone saw the thoughts and behaviors as exogenic – responses to outside messages – when they were often really coming from a brain problem within. I also remembered that while the brain was susceptible to disorder it is quite plastic – that experience, psychotherapy, nourishment, drugs, and love – all play a role in brain function. Parents know this better than anyone: we watch someone we know transformed into someone we no longer recognize.

I believe my daughter recovered because my husband and I understood that the thoughts and feelings she was experiencing were primarily biological and that with sustained nutrition and

therapy and love she could recover. We understood that her pathological drive for thinness, her phobia for certain foods, her social disconnect and her inability to see the seriousness of her situation were brain-based and temporary. I believe to this day that this understanding saved her life and saved us – her loving family – from sinking into despair and anger and blame. Notably, now aged 24 and fully recovered, so does our daughter.

This stance kept us focused on normalizing eating and behaviors. It helped us identify and work with better clinicians. It gave us a way to explain to other people what we were doing and why, but we did this against a backdrop of a professional world that did not just use different words – they actively discouraged the ideas. Certainly, no one treating our daughter mentioned that something might be different about her brain. I hear from countless families a year and this is still true for most.

When our family arrived at the offices of eating disorder specialists – and we consulted a number of them – they each told us they knew a great deal about our family, and our daughter's life, just on the basis of her diagnosis. In reality, I would argue they knew a great deal about her brain. Her symptoms were the same as most people with anorexia nervosa but her life was unique. With recovery she went from a person whose thoughts and behaviors were typical of anorexia nervosa to a person with genuine agency and free will. Her illness stole her individuality; her brain disorder temporarily derailed her. Recovery and learning to live well in her slightly different brain gave her back HER life.

I use 'brain disorder' to help parents understand that their loved one's brain is built and working differently, and that many of these thoughts and behaviors are understandable and common for those with an eating disorder. I use it to convey urgency and gravity – as deserving of family priority as any serious illness or injury. I use it to make clear that parents need not be distracted from their important care-giving role by wanting to find underlying issues – that is a witch-hunt that most often ends in blaming the patient.

Most of all, I use this term because parents have rarely heard much about how the thoughts and behaviors of an eating disorder could be biologically based, and while influenced by environment, do not necessarily reflect it. They do not know that the thoughts and even the exact words of patients are often so similar to others it could be a script for those with the same condition. Parents, unlike clinicians, have often never seen these behaviors or heard these pathological thoughts except in their own child. They generally have no idea that this is a temporary and treatable condition not the lasting beliefs and chosen lifestyle of their loved one.

I use this term and this orientation to take the emphasis off eating, off society, off parenting, off appearance – though they all are important. I use it to bring eating disorders into the category of obsessive-compulsive disorder, and anxiety disorders – and out of the category of willful behaviors and lifestyle choices. I find that saying brain disorder medicalizes the condition in a good and optimistic way by separating the present state of thinking from the true will and desire of the patient and by defusing conflict between parent and child. I say it to restore sympathy and make sense of what is otherwise incomprehensible.

I start with the brain – an organ of the body that is changed by and changes the environment as well as all body systems. The brain is nothing without the gut, the air, infancy, parenting, and society. However, to start outside the brain or to treat the brain as if it is only a sail in the wind of experience is both incorrect and cruel.

The evidence that the brains of people with eating disorder are different, often from birth, is becoming clearer. The more I learn about those differences, the more I appreciate the extraordinary work and courage successful treatment requires of patient, clinician, and family. Parents need to know how hard it is and why. We need to know that recovery must be protected by relapse prevention. We need to know that our loved ones' thoughts and emotions need nurturing and check ups just as do the bones and heart.

I find parents desperately want and benefit from a change of reference. Generally, we know our children and we know the culture we live in and we know what good and bad parenting is. We need help orienting ourselves to this strange and perplexing change. We need to set shift from viewing an accumulation of behaviors to seeing a distinct, identifiable problem. We also need reassurance that our loved one can be successfully treated. Even at the worst moments we need to know that the very traits that predispose our loved ones to an eating disorder are also often positive – ones that will serve them well in life after recovery; for example, empathy, sensitivity, conscientiousness, and care to detail.

Whether we all agree or not about the relative role of environment, nourishment, upbringing, wiring, and peers, we can all agree that eating disorders damage the brain. We are talking about young people and their brains at a crucial stage of development. Living with low or erratic levels of nourishment and high level of distress – these are part of the lifelong legacy to the organ, the brain. Parents naturally regard the brain as a critical organ – the home of our selves – under threat. We need to know that the risk of eating disorders is not simply of a medical crisis. It is a risk to the lifelong brain function of our loved one. We cannot afford dualism of mind and body especially because it treats body as if it does not matter to mind. There is no such separation.

We also have to consider possible harms in using the term ‘brain disorder’. Parents who are so inclined can interpret ‘brain disorder’ as something they have no power to change and no responsibility to address. We can mistakenly believe that the only solution to a brain problem is a pill. We can focus so much on calories and weight and physical measures that we lose sight of the whole person and the larger emotional needs beyond the eating disorder. Patients can be made to feel unlistened to; that they are just a diagnosis and a list of symptoms.

I do understand and stand with those who reject a deterministic view of brain function and eating disorders. Neuro-essentialism is no favor to our thinking here, and no favor to our friends the neuroscience researchers, who, while looking in their toolbox for answers, do not discount the tools and arts of other fields. We have to work together. The possible harms of any word choice exist, but how to manage the risk of harm is the job of those treating eating disorders as well as advocates like myself. Whatever term we use to explain an eating disorder to a family or to the media or to the patient, we are starting a conversation but should not stop there.

I believe we should not use the phrase ‘brain disorder’ if we do not care for it, but if we tell a family 100 words about society and one word about the brain we have set our compass in a certain direction. If the family has heard mostly about thin models and family dysfunction, but hears even a mention on the brain, it can be a revelation.

When we do use the term ‘brain disorder’ we align ourselves with people outside the narrow eating disorder world who use and understand this term; taking it out of the exclusive cul-de-sac of advocacy I find very much limits the eating disorders world. Sharing the terms used in the larger world of psychiatry and psychology we build bridges within fields, and we align ourselves as a community – a community that includes clinicians, researchers, parents and families and people like me at F.E.A.S.T. which represents thousands of families and clinicians and researchers in dozens of countries.

There is no perfect term, no one word or phrase that tells the whole story of an eating disorder or, indeed, any illness but this phrase represents an important shift in the field that is not always welcome. Yet the lack of language clarity reveals more than just disagreement about meaning; it perpetuates misunderstanding and argument. The ideas we are arguing about are not trivial and the lack of consensus tells us that there are genuine issues to resolve.

Despite the emotions, I do not believe this language difference, or the divide on what we mean by the terms we use, has to continue to be a pendulum swing to extremes or a win/lose battle between perspectives. I think the eating disorder specialty – with its uniquely multidisciplinary scope – is in a position to be a leader in mental health. Dr Insel of the NIMH said at our

recent F.E.A.S.T. conference that eating disorders are a rare example of optimism in mental health, because of the advances in successful interventions.

Language matters, but none of these disagreements over language are more important than our common goal – that of successful treatment for our sons and daughters and mothers and fathers and siblings and patients and friends. It is a priority that we come together on language because we are talking about a cluster of disorders that are not well understood and for which the treatments are notoriously poor. As a representative for parents, I do not ever lose sight of the reality that these are our children who die. Even survivors too often suffer lives of silent and isolated misery.

So, here is why I find the term ‘Brain Disorder’ important.

It recognizes shift from a primarily social to a more biologically oriented view of etiology

It implies urgency

It allows for invisible damage not dependent on our own preoccupation with weight statistics.

It calls for science literacy

It puts EDs in context with other illnesses

It acknowledges the challenge for the patient

It aligns with the larger mental health field

It focuses parents on what they CAN do

What it doesn’t mean:

An excuse to do nothing

An excuse to pity or condescend

Hopelessness

Environment and treatment don’t matter

Body image & eating concerns are invalid

That good parenting is not important

A friend of mine uses the analogy of a 1980s Walkman and a modern iPod touch. The two devices do the same basic thing, but the iPod draws from the experience of the past while adding technology only available now. And iPods, too, will be eclipsed later by more nuanced and refined tools. Words are just tools. But words matter.

How do families and patients respond to this language? I see a mixed response in parents. Some do respond with affront – feeling keenly all the stigma that society heaps on ‘mental illness’ and ‘brain disorder’.

It is my experience that the patients whose clinicians and families have taken a matter-of-fact stance toward the biological basis for brain disorders often feel HEARD, not insulted. They do not take refuge in lack of responsibility but feel understood for the enormous work they have to do to pursue successful recovery. I see families, even after years of unsuccessful interventions, transformed by the new knowledge that they are dealing with a genuine brain problem. With that new knowledge often comes new, effective, action.

The reaction that I hear most often is: ‘thank you’ which is followed by anger ‘why didn’t anyone tell me?’ The good news is that those who are deeply thinking about these issues are not that far apart, though they often only find that out after conflict forces them to talk. Are there extreme thinkers and fools? Of course – but they are ALL of our responsibility to address, and not an opportunity to use as ‘caution’ against reasonable ideas. If one’s best critique against an idea is that there are fools who believe it – the argument is sadly weak. I’m a parent, not a clinician but I am hearing so many professionals say ‘I’m afraid’ to speak up on this topic. I

"...destigmatises it...simpler to explain (her) condition to others, make them feel more comfortable in interacting with her and enlist their support." Belinda C.

"renewed determination to seek out effective treatment for my long-term suffering young adult daughter" Kris B., US

"led her to stop feeling that she herself was responsible for her disordered thoughts and self-destructive behaviors. She has room in her head now for hope, and is working hard with an excellent therapist towards accomplishing remission."

"I was beyond relieved as I always felt this as a mom."  
Becky

"With a background in Autism and Speech/ language pathology, after watching my daughter disappear, I knew this was a brain disorder complicated by malnourishment and behavior that could be modified /over-ridden/ re-routed."

"Knowing that it is a treatable brain disorder helped me to deal with my daughter's bizarre behavior and empowered me to help her recover. It really motivated me to feed her and get her well." Colleen

"allows clarity in how to understand how the sufferer difficulties and how to support them in a way that results in healing from the core - rather than managing symptoms in a holding pattern forever."

"Biological Language has FREED me so that I can help my daughter beat this disease. It has empowered me." Alida R.

"made me feel empowered and became the foundation of my recovery." Katie

think we will all be hearing more from families and colleagues in this new era, on language and on science.

Finally, I propose that even the term brain disorder is inadequate. What we need is to give it meaning with one additional word: 'Treatable Brain Disorder'. Without that extra word, all our worst fears of hopelessness and of biological determinism thrive. The skills of psychotherapy and the skills of parenthood are pivotal in eating disorder treatment, not in spite of brain problems but because that is the way the brain is uniquely and exquisitely designed.

**Notes on contributor**

**Laura Collins Lyster-Mensch**, MS is a writer from the USA who became an activist for improved eating disorder treatment after the recovery of her teen daughter from anorexia. Her book, *Eating with your anorexic* (McGraw Hill), is a memoir of her family's experience. She is the Executive Director of F.E.A.S.T., an affiliate member of the Academy for Eating Disorders, volunteers with the Eating Disorders Coalition, and ANAD. She has been an invited speaker for the National Eating Disorders Association, the Academy for Eating Disorders, Renfrew Foundation, Ophelia's Place, the University of North Carolina Eating Disorders Program, and Eating Disorders Coalition conferences. She writes a blog for the *Huffington Post*, and is also frequently interviewed by the media, including *The Washington Post*, *The New York Times*, *BBC News*, *Wall Street Journal*, *Newsweek*, *NPR*, and the *Los Angeles Times*. Her personal blog appears at [LaurasSoapBox.net](http://LaurasSoapBox.net).